# *Original Research Article*

## Pharmacy and Medicine Students' Self-assessment of their Knowledge about Rare Diseases


### ABSTRACT

**Aim:** The aim of this study was to describe the knowledge of pharmacy and medicine students about rare diseases.

**Methodology**: This is a cross sectional study that was conducted in January 2021. The study included a questionnaire that was adapted from a previous study. The questionnaire was translated to Arabic and after validation it was converted to online form to be filled by the students.

**Results**: Most of the students were pharmacy students (60.78%) and the majority of them were females (72.55%). Only 11.76% of the students reported that their knowledge is very good about rare diseases. About 52.94% of them said that they are prepared for caring for patients with rare diseases. The majority of the students agreed that they need to broad their knowledge about rare diseases (97.06%). More than half of the students said that they get knowledge about rare disease from internet (51.96%) and scientific literature and research (48.04%)

**Conclusion:** The present study showed poor knowledge of pharmacy and medicine students about rare diseases. There is an urgent need to raise the awareness of medical students on rare diseases and educate them about these diseases by adding a course on rare diseases in their medical curricula.




**Keywords:** *Knowledge, medicine students, pharmacy students, rare diseases.*

## INTRODUCTION

Rare diseases are diseases that affect a small number of people compared to general populations. Nowadays, rare diseases have received a global attention [1]. The meaning of rare disease is different between different regions [2]. In the European Union, a disease is classified as rare if less than 5 persons are affected out of 10,000 people [2].

A disease is defined as rare when it affects less than 1 per 2000 people as reported by The Saudi Ministry of Health [3]. Most of these diseases result from genetic disorders and occur at birth but some of these diseases might emerge at older age. These diseases are considered one of the major concerns of general health and constitute a heavy burden to society [3].

Approximately 6000 to 8000 rare diseases have been detected [3]. Types of rare diseases included psychiatric, cardiac, dermatological, chromosomal, endocrinological, communicable, orthopedic and urological diseases. Some of these rare diseases, such as albinism and hemophilia have common names known to the public [3]. In general, there are no effective treatments to these diseases [3].

Inadequate expertise of the healthcare workers proved to be a major problem in the highly specialized treatment process of rare diseases [4]. People with rare diseases often face several challenges, due to the low prevalence and the lack of knowledge of healthcare providers [4]. A previous study in Belgium showed that the average level of knowledge on rare diseases is suboptimal among physicians [5].

Genetic disorders such as glucose-6-phosphate dehydrogenase deficiency, hemoglobinopathy, autosomal recessive syndromes in addition to numerous metabolic disorders have a presence throughout the Middle East [6,7]. Yet other rare diseases may not have a genetic cause but rather result from allergies or viral or bacterial infections [7].

Poor knowledge on rare diseases results in a significant delay in the diagnosis and treatment of these diseases [8]. So it is important to increase the awareness of healthcare workers regarding these diseases and also it is important to increase the awareness of medical colleges' students about these diseases. Thus, the aim of this study was to describe the knowledge of pharmacy and medicine students about rare diseases.

## METHODOLOGY

This cross sectional study was conducted in January 2021 to describe the knowledge of pharmacy and medicine students about rare diseases. The study included a questionnaire that was adapted from a previous study about the knowledge and opinions of medical students regarding rare diseases in Poland [9].

The questionnaire was translated to Arabic and after validation it was converted to online form to be filled by the students. The study included pharmacy and medicine students, so other university students were excluded from the study.

The questionnaire consisted of 2 parts; the first part about the sociodemographic characteristics of the students and the second part included the main questions regarding students' knowledge about rare diseases.

The data was processed using Microsoft Excel and the descriptive data was represented as frequencies and percentages.

## RESULTS AND DISCUSSION

The questionnaire was filled by 102 students. Most of the students were pharmacy students (60.78%) and the majority of them were females (72.55%). The sociodemographic characteristics of the students were shown in table 1.

**Table 1**. Socio-demographic characteristics of the respondents

| Variable | Category | Number | Percentage |
|---|---|---|---|
| College | Pharmacy | 62 | 60.78 |
| | Medicine | 40 | 39.22 |
| Years of study | 5 | 62 | 60.78 |
| | 6 | 40 | 39.22 |
| Gender | Female | 74 | 72.55 |
| | Male | 28 | 27.45 |
| Marital status | Single | 98 | 96.08 |
| | Married | 4 | 3.92 |

Only 11.76% of the students reported that their knowledge is very good about rare diseases. About 52.94% of them said that they are prepared for caring for patients with rare diseases. The majority of the students agreed that they need to broad their knowledge about rare diseases (97.06%) and 77.45% of them said that the medical curricula should include a mandatory course on rare diseases.

More than half of the students said that they get knowledge about rare disease from internet (51.96%), scientific literature and research (48.04%) and scientific conferences and symposia (31.37%). Students' self-assessment of their knowledge about rare diseases is shown in table 2.

**Table 2**. Students' self-assessment of their knowledge about rare diseases.

| Variable | Category | Number | Percentage |
|---|---|---|---|
| How would you rate your knowledge about rare diseases? | Very good | 12 | 11.76 |
| | Fair enough | 28 | 27.45 |
| | Insufficient | 43 | 42.16 |
| | Very poor | 19 | 18.63 |
| Do you feel prepared for caring for a patient with a rare disease? | Yes | 54 | 52.94 |
| | No | 10 | 9.80 |
| | I do not know | 38 | 37.25 |
| Would you like to broaden your knowledge about rare diseases? | Yes | 99 | 97.06 |
| | No | 2 | 1.96 |
| | I do not know | 1 | 0.98 |
| Do you think that there should be a mandatory course on rare diseases in medical curricula? | Yes | 79 | 77.45 |
| | No | 12 | 11.77 |
| | I do not know | 11 | 10.78 |
| Have you had any classes about rare disease during your studies? | Yes | 52 | 50.98 |
| | No | 34 | 33.33 |
| | I do not know | 16 | 15.69 |
| Where do you get your knowledge about rare disease from?* | Mandatory courses at the university | 19 | 18.63 |
| | Faculty courses at the university | 18 | 17.65 |
| | Scientific literature and research | 49 | 48.04 |
| | Scientific conferences, symposia | 32 | 31.37 |
| | Internet | 53 | 51.96 |
| | I do not search for such information | 20 | 19.61 |

*The respondents can choose more than one answer.

The present study showed that the majority of the students have poor knowledge about rare diseases but they showed a positive attitude towards broadens their knowledge about rare diseases and to include a mandatory course on rare diseases in their curricula.

Similar to the results of the present study, Domaradzki and Walkowiak reported a poor knowledge about rare diseases (only 4.6% of the students had a good knowledge) [9]. Furthermore, they reported that 46.5 % of the students agreed that their medical curricula should include a mandatory course on rare diseases [9]. Several studies also found that medical students often do not receive necessary training in rare diseases [8,10-14].

Walkowiak and Domaradzki conducted a study about teaching rare disease topic for nurses and nursing students in Poland and reported that the knowledge of rare diseases among nurses and nursing students seems to be insufficient [15]. They also stated that nurses and nursing students declare a low training level in rare diseases and do not feel adequately prepared for caring for rare diseases patients [15].

Most of the students in the present study said that they get knowledge about rare disease from internet mainly followed by scientific literature and research and scientific conferences and symposia. Similarly, Domaradzki and Walkowiak reported that 59.8% of the students in their study get knowledge about rare disease from internet [9].

Almalki et al stated that the problem of rare disease and orphan drug is a global problem [7]. They also stated that international discourse and cooperation should be at the top of every country's list of relevant policies [7].

## CONCLUSION

The present study showed poor knowledge of pharmacy and medicine students about rare diseases and most of the students get their information from internet. The students should be advised by their university staff to find the information from trusted sources not from internet. Moreover, there is an urgent need to raise the awareness of medical students on rare diseases and educate them about these diseases by adding a course on rare diseases in their medical curricula.



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